

The Home-Based Care Alliance Newsletter



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“What we are hoping for is greater collaboration between government and NGOs because this is what will make the difference.”

-ICA Lambassa, Benin

Global Advocacy Updates & News



Maxensia Nakibuuka spoke at a session on the achievement of MDG 6 to combat HIV/AIDS.

United Nations High Level Meeting on AIDS, New York City

Ten years since the UN General Assembly Special Session on HIV/AIDS, UN member states convened from June 8th-10th to review the 30 year effort to stymie the AIDS pandemic. While the declaration to redouble efforts to achieve Universal Access by 2015 was well received, the missing link between reaching zero and making clear investments in caregivers who are poised to take on this challenge was overshadowed. As part of the Caregivers Action Network the Huairou Commission organized a side event that was co-sponsored by the Mission of Japan, the Mission of Kenya, UNDP, and UN Women, under the banner "Universal access to prevention and treatment is impossible without care and support." During the event a representative of the National AIDS Council of Kenya outlined the country's national plan which includes direct investment in community caregivers. The Huairou Commission commends the government of Kenya for supporting a community AIDS response that we believe is the only way to end this pandemic.

Grassroots Leader Appointed to the Global Coalition on Women and AIDS Steering Committee

Congratulations to Violet Shivutse of GROOTS Kenya and the Kenyan HBCA for her nomination to the Global Coalition on Women and AIDS (GCWA) Steering Committee. Violet's nomination represents the first time a grassroots home based care leader has held a seat on the GCWA. This opportunity will elevate the work of home based caregivers, and grassroots women in general, as Violet moves to ensure their voices and priorities, as frontline responders to the AIDS pandemic, are authentically presented on the GCWA. Violet is the founder and director of Shibuye Community Health Workers, a focal point leader in GROOTS Kenya, and a key innovator of the Community Watch Dog Group, a partnership and accountability tool which is stopping and redressing land grabbing from widows and orphans across Kenya.



Violet Shivutse

Benin Caregivers Take the Lead When Government Does Not



We started to work as caregivers in 2007 because in our communities there were people living with HIV and AIDS and no one was volunteering to help them. After participating in a Grassroots Women's International Academy on Home-Based Care, we decided to establish a Home-Based Care Alliance, with the support of the Huairou Commission and GROOTS International, because we noticed that no one else was prioritizing what was happening to these individuals except for home based caregivers. We started to sensitize community members about HIV and AIDS through the Alliance and we have found the organizing process very helpful for the communities we work with in Benin. We are connected to the people we care for not simply because they are our community members but because we are with them, caring for them and counseling them. We have trained volunteers who provide care to people in need and we also have two staff members who make fields visits each week to follow-up on any issues brought forward by our volunteer caregivers. Our caregivers are able to provide closer and more personalized assistance to people in need and this is something that the government officials have failed to do and are not providing funding for so that others can. Government officials are removed from our daily realities and though the work is physically and emotionally tiring, our caregivers enjoy this work and are willing to accept new cases because this is also a sign that more people are revealing their status. Our main obstacle to organizing the HBC Alliance in Benin is a lack of funding. Caregivers are working without any support or compensation and thus it's difficult for our organization to mobilize more women to do this work. What we are hoping for is greater collaboration between government and NGOs because this is what will make the difference. Our vision is to continue this work in order to mobilize more women around this project. What gives us hope for the future is that one day this work will be recognized by all and more support and resources will be directed towards it.

-Reported by Adaman Aboudoulaye, Yvonne Toffodji and Kassimou Issotina of Lambassa ICA

Providing Care for Half a Lifetime: Caregiver Spearheads Zambian HBCA

My name is Milliah Mhlanga, I am 62 years old and I live in Desai compound in Lusaka, Zambia. I belong to the **Zambia Homeless and Poor Peoples Federation (ZHPPF)** HBC and I have been a home based caregiver since I was 30 years old, though I was only trained formally as a caregiver eight years ago. I used to offer my help voluntarily to people in my area. I used to assist those that had been discharged from hospital but were not yet strong enough to do household chores. My service did not go unnoticed by the community, thus when an opportunity came for palliative care training, I was selected to do the training. People saw how committed I was and through my continued commitment, I



was chosen as a leader. My community wanted others to learn from my example of commitment. We are doing a lot in our community, but it is not recognized by the government. For this reason, when time came to form the Zambian Home-Based Care Alliance I took the lead. I wanted our efforts to gain recognition. If I compare the situation 30 years ago when I started giving my services to the community, I can see now that the burden is becoming more. As home based care givers we have more to do now. Thirty years ago I used to see an average of two people per month but now I have over 20 people on average to take care of every month. There are more people that the hospitals are discharging who still need care. The nurses and doctors at the hospital never make follow ups on the patients they discharge; it is up to people like me to take care of them until they are strong enough.

One moment that inspired me was when we had a patient in our community who needed 24 hours care. I could not manage to do this alone. I informed other caregivers and we took turns to take care of her until she died. This made me realize that we needed to work together even though we were trained and reported to different organizations. Also, as we worked, we shared our experiences from which I noticed that we were basically facing the same challenges. These challenges could only be addressed if we united and spoke with one big voice. As a caregiver I provide comprehensive care to the patient. A nurse will give medicine but will not take care of other needs such as washing the patients (especially those bedridden who cannot manage to walk to the restroom). Also as a caregiver I develop a relationship with the patient which nurses rarely do because they have shifts and may be assigned to a different ward. But as a caregiver the patient will see me every day and we have more time for discussion which helps build trust. They look to me not as a caregiver but as their grandmother, mother, sister or aunt. Such care is not provided for by government workers. As we try to form the HBC alliance we have to do a lot of movements to meet caregivers in other parts of the district, and this cost money. We have to limit our movement depending on money available. I would have liked it if the whole country was covered in the formation of an Alliance but that is a challenge. If government and NGOs were to assist us, we would appreciate it and make an alliance that covers the whole country.

My vision for my community is that we should be able to have caregivers who are recognized by the government within our community. NGOs come and go but we shall always be with our government. If the government recognized us as workers, then we could have a continuation of HBC services in our community. My vision is also to see that we have viable income generating activities in our community that would provide funds to assist the clients in our community. There are times when as a caregiver, I use my own funds to assist where there is a pressing need. I have hope for the future because the few meetings we have had so far in planning to form the alliance have shown me that we can do it. We have the confidence and we are united even though we are coming from different organizations.

“[Patients] look to me not as a caregiver but as their grandmother, mother, sister or aunt. Such care is not provided for by government workers.”

-Milliah Mhlanga, ZHPPF

Two Caregivers Reflect on Caregiving in Nigeria

My name is **Bola Yusuf** and I am a home-based caregiver in Nigeria. I joined the Home-base Care Alliance through the IWCC caregiver program and I am also a member of IWCC's monthly contribution of micro loan and finance. I became a home base giver because I am also living positive since 2004 when I was diagnosed with HIV. I was sick and no one was there for me. My family members deserted me. One day a friend told me about IWCC's support group that was doing home based care and support for infected people and also supported the affected members of the family. IWCC's team of caregivers took care of me through my sick period and during this time, I promised God, that if I got better I would become a home based caregiver for other sick people. I became a leader because I started a support group for people living positive. I link other positive living people (PLP) to IWCC's program and I go from house to house to remind people about our group meetings and to collect our monthly contributions to support each member in the group. Because of this trust, which they have given me, I became a leader and started our own support group called the Golden Sister group. It is this group that is now joined to IWCC's Home-Based Care Alliance. My connection with the people I care for is that they live in our community, they are



Above: Caregivers attending an IWCC meeting for the HBCA

the ones who provide care and support to the sick. The government is not going to people's houses to bathe them, clean their homes, help them cook and give them food supplements. My work as a caregiver and community organizer was a result of my commitment to do volunteer work for my community people and to help those who are sick with HIV like me.



Above: The Director of IWCC Limota Goroso Giwa provides care to two boys

My name is **Hajia Falilat Soliu** and I became a caregiver because of my desire to help people living with HIV. When I was diagnosed with HIV in 2007 I thought it was a death sentence. Other caregivers came to me and supported me and because of this I decided to start a small group of caregivers in my area. I have since become a leader in the movement and our group has joined the Home-Based Care Alliance in Nigeria. I am connected to the people in my community and I am committed to them because we are neighbors and also living positively. Our care work includes home visits and re-visits because ARV adherence is critical. We cook, clean the house, and bathe the sick person and we sometimes refer clients to the hospital for opportunistic infections that emerge. The government cannot do this kind of care work so it is women like me who volunteer to take on caregiving because it has affected me personally. I am a community organizer, HIV positive leader, and I am not compensated for my contribution to reducing the AIDS pandemic in Nigeria.

The **International Women's Communication Center (IWCC)** has been leading the Alliance organizing in Nigeria since 2005. Their network of caregivers links and organizes 500 home based care givers from over 50 women's groups. IWCC is using monthly meetings of group leaders to track Alliance registration, discuss successes and challenges of local organizing and to unify advocacy and outreach efforts to national and local governments around lobbying efforts. Right now IWCC's challenge is with formalizing local level Alliances because of the bureaucratic paperwork that is required to become recognized (this includes bank statements, constitutions and letters of accreditation from government hospitals). IWCC believes that the Alliance organizing has empowered local women to move into political spaces confidently because they have the support of a several hundred caregivers behind them. IWCC's outstanding plans for their Alliance Monitoring and Evaluation are to develop community watchdog groups that will build new leaders and to continue community sensitization and advocacy around HIV prevention.



Overcoming Obstacles and Transforming Community in Jinja, Uganda

I became a leader in my community because I was a woman who had social work and social administration experience through my six year affiliation to the Christian Children's Fund that was helping children from needy families here in Jinja, Uganda. During that time, I learnt and saw the experiences women who were going through serious challenges such as evictions from their homes by Jinja Municipal Council enforcement officers, women who were affected and infected by HIV/AIDS, old age, unemployment and lack of good habitable shelters. Being a person who was inspired to help others I became a leader by initiating and mobilizing fellow women in my community.

I was moved after seeing so many women who lost the chance of purchasing land in their own name and they accepted to be bought at a [reduced] price especially women who were HIV/AIDS positive, the elderly and unemployed women. This was the gist of mobilizing women in order to have a strong voice so that our problems could be heard by those who could give help. Indeed, we got funding as a group. I was inspired when Uganda Community Based Child Welfare (UCOBAC) invited me and trained us in HBCA in Mukono in 2008. I am connected to the people I take care of as a counselor, an advocate, a friend, and a care giver. I am a facilitator, a leader, an advocate and organizer. **Where government is successful is the provision of medication but they cannot provide the time to take care of the sick, destitute and elderly in their respective homes.** Managers work through people I therefore assign responsibilities to staff and together we organize the Home Based Care Givers to bring services to vulnerable groups of people. The big challenges I meet while organizing the Alliances is transport to different areas, resources for holding trainings, to provide protective gears and lack of recognition in the community where we serve.

The obstacles that we face are a lack of funds to provide food stuffs to the sick, long working hours and long distances from one client to another. The greatest challenge that we face is by Government and NGOs to formulate policies that appreciate the caregivers contribution through compensation for their difficult work and the lack of transport for caregivers to do their work and provide service delivery and take sick patients to hospital. My vision for the Home-Based Care Alliance is to see their contribution recognized, appreciated and compensated locally, nationally and globally. Some funding agencies have started to appreciate the work of home based care work and are putting forth calls for proposals related to this work. In Uganda, the Home-Based Care Alliance has transformed our community by motivating more community members to become involved in the effort.

—Reported by Joyce Nangobi of Slum Women's Initiative for Development

What is the Home-Based Care Alliance?

The **Home-Based Care Alliance (HBCA)** is a bottom-up federation of grassroots home-based caregivers across Africa. These caregivers are primarily taking care of people living with and affected by HIV and AIDS. They also care for people with other chronic illnesses, the aged and others in their communities who are in need. Although home-based care is a vital, life-giving service in communities, most formal health systems, governments and donors do not recognize caregiving for how important it is, and do not include caregivers or their work in their decision-making or resource allocation. So caregivers, most of whom are women, shoulder this burden alone.

The purpose of the Alliance is for home-based caregivers to come together, better coordinate their work, and advocate for recognition, inclusion in formal decision-making structures, and for resources to support their contributions. The work of the Alliance happens locally, nationally and globally. The Alliance members and leaders are grassroots caregivers themselves. NGO staff are principled partners and provide technical support when it is needed.

What is the Difference Between Home-Based Care Work and the HBCA?

Home-based care is the assistance and support given to people infected and affected with HIV and AIDS at home. HBC includes a wide range of services, including nursing care, home visits, assistance with household chores and caring for children, linking to health facilities and social services, psychosocial and nutritional support, training family members to care for the sick, and many other things.

The Home-Based Care Alliance, on the other hand, is a platform that brings together caregivers with a common vision to have one strong collective voice for advocacy. The components of Home-Based Care Alliance work include lobbying and advocacy, resource mobilization, empowerment and organizing caregivers.

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The Home-Based Care Alliance newsletter is a resource for sharing information and updates between grassroots members of the Home-Based Care Alliance across Africa and for sharing relevant information from the global level with grassroots caregivers. If you are an active member of the HBC Alliance and have news to share about your efforts to gain recognition and resources for caregivers in your community and country, please write to us at our HBCA Blog at <http://homebasedcarealliance.org/>